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## **Part two: The body over the lifecourse**

### **Chapter 7: Exploring experiences of ageing with Type 2 Diabetes (T2D): The case for a whole-system approach**

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This chapter discusses:

- Type 2 Diabetes (T2D) in context
- Managing T2D as a long-term condition
- Type 2 Diabetes and empowerment
- Day-to-day management of T2D
- Social, familial, interpersonal and healthcare professional roles in T2D self- management
- The role of health system factors in T2D self-management
- T2D-related factors and their influence on self-management
- Socio-contextual factors and their influence on self-management

## **INTRODUCTION**

Diabetes is a long-term condition that affects multiple areas of daily life, and as such must be managed on a day-to-day basis by the diagnosed individual, often with the help of their family and/or carers. The prevalence of Type 2 Diabetes (T2D) is growing amongst the older population with risk factors for T2D increasing with age, hence, overall rates rise as the population ages (Diabetes UK, 2010). T2D is a growing issue for older people and supporting the self-management needs of older people living with T2D is one way of helping people to experience their later years positively. Day-to-day management of T2D includes self-care tasks such as monitoring blood sugars, regular exercise, following prescribed dietary measures, and medication-taking (taking tablets as well as other exogenous insulin therapies). When this set of behaviours occurs the patient

is said to be self-managing their condition. However, as this chapter explains, attaining T2D self-management is not as simple as it may appear as a multitude of factors shape older people's ability to self-manage T2D. The chapter begins by looking at recent research on older people's day-to-day perspectives, understanding the experiences of self-managing T2D. The chapter then moves on to explore how social, familial, interpersonal and healthcare professional relationships impact on how older people self-manage T2D. However, we also demonstrate that the healthcare system plays a role in the factors that shape T2D self-management, as do T2D-related factors such as progression of the illness and the presence of co-morbidities. We then briefly look at wider socio-contextual factors – such as income and ethnicity - and their influence on self-management. We conclude by arguing that to truly empower older people to self-manage and age positively with T2D, it is important to address all the factors that shape self-management.

## **TYPE 2 DIABETES (T2D) IN CONTEXT**

Diabetes Mellitus is a definition given to a group of heterogeneous metabolic disorders characterized by elevated blood glucose concentration (Foundation of European Nurses in Diabetes (FEND), 2011). Diabetes Mellitus is classified in a number of ways, the most prevalent categories being Type 1 Diabetes (T1D) and Type 2 Diabetes (T2D). Generally T1D occurs when there is no production of insulin in the beta-cells of the pancreas, which results in elevated blood glucose levels and the need to frequently administer exogenous insulin (O'Rahilly, 2006). In the majority of cases the onset of T1D occurs in childhood. T2D on the other hand, is generally associated with onset in later life (aged 50+) – and is a loss of response to the action of insulin, known as 'insulin resistance' as well as beta cell destruction (FEND, 2011). In 2010, Diabetes UK estimated that there were 2.6 million people diagnosed with diabetes in the UK, 90 per cent (n=2,213,136) of whom had T2D.

In all types of Diabetes Mellitus, it is the body's inability to produce or respond to insulin which increases blood glucose concentration, this causes the blood to thicken, which adversely affects the systemic functioning of the body - particularly the circulatory system (FEND, 2011). This leads to the symptoms and further pathologies of Type 2 Diabetes. The morbidities of diabetes are predominantly micro- and macro-vascular in nature, and can result in severe complications such as cardio-vascular disease, blindness and amputation (O'Rahilly, 2006). T2D is, hence, associated

with higher morbidity rates across the lifespan (Diabetes UK, 2010). Diabetes was the eighth most common cause of death globally between 2000 and 2012 (World Health Organisation (WHO), 2014), and in England, for example, more than one in ten (11.6 per cent) deaths among 20 to 79 year-olds can be attributed to diabetes (Diabetes UK, 2010).

Internationally there is growing concern surrounding the high prevalence of T2D, in particular high mortality rates and shortened life expectancy (O’Rahilly, 2006; Diabetes UK, 2010). In the United Kingdom (UK) life expectancy is shortened on average by 10 years by living with T2D (Diabetes UK, 2010). As a long-term condition, T2D represents a case where early diagnosis is crucial to good health outcomes, and where the subsequent ability to respond to the illness through ‘lifestyle changes’ and medication taking - as well as access to healthcare information and the support of health service provision - has an ameliorative effect on health outcomes in terms of quality of life, morbidity and mortality (British Medical Association (BMA), 2004; Diabetes UK, 2010; FEND, 2011). The adverse impact of T2D also extends to the effects that complications can have on people’s lives - around half of all people living with T2D are living with complications of the condition, many of whom often developed these complications before diagnosis (Diabetes UK, 2010). The burden of the disease that T2D represents for health systems is also a concern – for example, the costs to the UK National Health Service (NHS) was estimated to be around £1 million an hour (Diabetes UK, 2010).

One factor contributing to high prevalence of T2D is the ageing population. One-in-twenty people over 65 years of age have T2D, rising to one-in-five for those 85 years or above. Therefore, internationally, initiatives have focussed on screening the older population at the primary care level (FEND, 2011). Focusing on the prevalence and treatment informs service provision and the deployment of health resources, hence it is important to note that social factors have been shown to play a role in T2D-related prevalence. For example, in the UK, ethnicity has been identified as a factor in the prevalence of T2D, particularly in those of an African-Caribbean or Asian origin - a three- to six-fold increased prevalence respectively when compared to the white population (DoH, 2001). T2D has a more common prevalence in socio-economic groups with lower incomes – The British Medical Association link these two demographic factors to low birth weights and obesity brought about by poor diet (BMA, 2004). Interventions tend to target individuals who are

seen to have 'deficits' in healthy behaviours. However, the social patterning of wider illness by socio-economic status is well established in the UK literature, the main factor implicated being unequal access to health-protective resources due to mal-distribution of wealth (Scambler, 2009). In the North East of England, for example, T2D prevalence is 28% higher for men and 45% higher for women in the most deprived areas, compared to the regional average. Also in terms of health outcomes, people living with T2D have a higher risk of both morbidity and mortality which is further exacerbated and confounded by ethnicity, social class and increased age (Connolly, 2006; NHS National Diabetes Service, 2012). It is important to note that the vast majority of managing T2D is conducted on a day-to-day basis by people living with diabetes (self-management of T2D). However, more recent data suggest that variations in morbidity and mortality are not associated with lifestyle alone, but rather access to health promoting resources and disparities in healthcare provision (NHS National Diabetes Service, 2012). This suggests that factors shaping the prevalence of, and outcomes for, T2D are multifactorial and need to be addressed through a whole system approach if people are to have positive experiences of ageing whilst living with T2D.

## **MANAGING T2D AS A LONG-TERM CONDITION**

As we have seen the determinants of T2D are multi-factorial, yet systematic reviews of the literature show that blood glucose level is the most commonly researched dimension of diabetes management (Van Dam et al, 2003; Nam et al, 2011). In fact this aspect of diabetes research is the primary focus of some of the largest national studies of diabetes such as The Diabetes Control and Complications Trial Research Group and the United Kingdom Prospective Diabetes Study. The main thrust of these studies being that maintaining control of the metabolism - through strict adherence to dietary, insulin and non-insulin therapy, and regular exercise - can ameliorate symptoms of diabetes, as well as delay and decelerate complications. Therefore, within the research literature there is also growing concern with the frequently poor 'adherence' or 'compliance' to clinically recommended diabetes-related regimens, in spite of public health interventions as well as concern about the impact of T2D on the quality of life of the older people affected (Lawton et al., 2003).

Psychological research points to affective, cognitive and behavioural aspects that influence the capacity to self-care. Research in this vein investigates how factors such as personality and

behavioural dispositions (Knight, Dornan and Bundy, 2006); belief in the ability to perform a task – or self-efficacy (Funnell and Anderson, 2004; Anderson et al., 2009); and perception of risk (Asimakopoulou et al, 2008) - to name but a few - all influence patients' capacity to self-manage. As such, 'control' and 'management' of T2D are measured as maintaining a blood glucose level as close to that of the population without diabetes as possible. In contrast, Diabetes UK (2010) note that although such studies show utility in justifying or evaluating clinical courses of action, they do not take into consideration the *personal and social barriers* people experience in attaining, and maintaining adherence to the T2D therapeutic regime. A growing body of research is also developing which seeks to enhance studies of prevalence and adherence by looking at psycho-social aspects of T2D, i.e. how people live with T2D on a day-to-day basis. A key drive in these studies is to explore factors that inhibit or enhance the capacity of older people living with T2D to self-manage, and age positively, with a long-term condition, and to investigate factors that constrain and enable access to supportive social environments that improve health (Gomersall et al., 2011).

## **Type 2 Diabetes and empowerment**

Over the past 15 years, the adherence approach to patient care has been supplanted by empowerment models which seek to create an equipoise situation whereby professionals' clinical and bio-medical expertise, and patients' 'lay' expertise, complement one another in the management of T2D (Asimakopoulou et al., 2012). Empowerment, as a concept, is based on the assumption that individuals, if given the freedom to choose and the opportunity to reflect, will be able and willing to select appropriate diabetes goals – which can then be facilitated by the healthcare professionals' knowledge of the clinical realm.

This emphasis on patient-led, self-directive approaches which promote shared decision-making with healthcare professionals – a direct challenge the adherence model – can be linked to wider trends in international healthcare which seek to involve people living with T2D in healthcare decision-making (Coulter, 2002). Its adoption in T2D management is also linked to the oft cited assertion that although professionals are the clinical experts in T2D management, patients are experts in living with diabetes by virtue of managing T2D on a day-to-day basis (Nam et al, 2011;

Corser; 2010). Hence, within the approach the experiences of older people living with T2D are a key focus of attaining positive self-management of the condition.

### **Older peoples' day-to-day perspectives, understanding and experiences of managing T2D**

The bulk of the work looking at the 'day-to-day' strategies people adopt to manage T2D are explored from the perspective of the patient (Nam, 2011). Kelleher's (1988) seminal work on managing diabetes suggested that maintaining a 'normal' life was a key concern for people managing diabetes. A central construct of the study was exploring the ways people managed their illness to minimise disruption to their lives, i.e. ways the condition "impinged" on their day-to-day lives (Kelleher, 1998). The study found three main styles in which people managed diabetes: Copers who 'strategically managed' their illness by pre-emptively adjusting diabetes-related activities - such as timings of food to reduce 'impingement'. Normalisers organised their daily routines and activities around their symptoms and care responsibilities, and hence were seen as complying to advice rather than 'taking charge' of the condition. The final sub-group were worriers/agonisers who tended to report being unwell, and having poor control over their condition leading to heightened anxiety.

Maclean's (1991) seminal work explored the factors that people living with diabetes had for 'adhering' or 'not adhering' to self-management dietary advice. The research also found that, with experience, people living with diabetes were able to use their knowledge and awareness of changes in their body to inform management of diabetes, as opposed to more didactic information. Maclean also charted further factors found to influence patients' responses to dietary requirements and their self-care. These being:

- Individual factors: Food history, coping skills, character traits, and gender
- Diabetes factors: Severity, duration, experience and threat of complications
- Contextual factors: Family support, peer support, professional support, social norms, access and availability of self-monitoring equipment, and occupation.

Maclean (1991) developed a continuum of dietary-management styles ranging from: those who followed a strict diet plan; those who introduced a moderate to high degree of flexibility; to those who never, or rarely, adhered to dietary advice. It was noted that participants' views consistently

reflected an inherent tension with regard to following dietary measures. This tension related to conflicts between the benefits for biological health (usually expressed as a bio-medical measure or increasing longer life expectancy) and feelings of well-being (a subjective sense of normalization, self-esteem and belonging through social integration). The underlying principle Maclean formulated was that where the pursuit of biological health did not compromise well-being, adherence was seen by respondents as less problematic. However, when the pursuit of health conflicted with well-being - individuals became more flexible with their care in order to minimize the perceived restrictions on well-being. This suggests that the people develop underlying perceptual schema relating to how to manage their condition, based on balancing how recommended self-management practices conflict with participating in everyday life, i.e. that positive experiences of self-management involve people adapting clinically recommended behaviours when they feel it necessary.

This idea of overcoming the 'restrictions' that T2D self-management places on day-to-day living is a key premise of numerous studies (e.g. Collins, et al., 2009 and Ockleford et al., 2008). In fact, the process of balancing clinical concerns against well-being concerns has been a consistent finding in T2D-related patient experience research (Campbell et al., 2003). Brewer-Lowry et al. (2010) sought to explore the perceptual differences between those who did and did not meet clinically recommended behaviours. The study found that those who met clinical targets gauge their self-management tasks in concrete terms and specific terms, as opposed to less structured descriptions given by those who did not meet clinical targets. This concept of an ability to purposively and strategically respond to T2D as a mediator of T2D self-management is a theme in the literature on day-to-day management.

More recent work has continued to develop typologies based on the degree of purposive action undertaken by the individual with T2D. Collins, et al. (2009) explored perceptions of self-care coping strategies in people living with T2D according to self-care health value (the value the patient placed on their diabetes self-care in relation to their health); self-care responsibility (how self-care tasks were divided between self and others), and how the individual planned for, monitored and responded to the necessities of self-care. Three self-management types were identified:



- ‘Proactive managers’ who were self-directed, valued improving long-term health through self-care, and could independently maintain metabolic control through planning.
- ‘Passive followers’ followed their prescribed self-care regime and valued it, but did not react pre-emptively or autonomously to make changes to metabolic control; and
- "Nonconformist" patients who do not follow recommended self-care practices (ibid.).

Although looking at what people do ‘well’ to achieve self-management targets is a useful exercise, it is questionable whether people’s perceived success in self-managing T2D should be underpinned by the ability to hit externally defined clinical targets which are experienced as a barrier to participating in day-to-day life. As such, it would appear that older people experience do barriers that require them to make sacrifices in aspects of their wellbeing they perceive as positive, in order to successfully ‘adhere’ to clinically recommended behaviours.

### **Day-to-day management of T2D**

Thus far, we can see studies have focussed on codifying and categorising behaviours based on how people normalise the management of the day-to-day restrictions of T2D, and how they purposively or strategically people living with T2D manage these restrictions. Equally, studies have looked at patients’ perspectives of T2D self-management to explore barriers and enablers experienced in the day-to-day aspects of the T2D self-management regimen – with some commentators such as Maclean (1991) fusing both elements together. Exploration of barriers and enablers to T2D management are usually conjoined with suggestions of how to support patients to self-manage. Hayes et al (2006) explored the task of T2D medicine management from the perspective of older people living with T2D, and found three main issues:

- The inconvenience that administration of T2D treatments had on patients’ lives,
- Patients’ desire to avoid injections and insulin therapy, and
- The physical and emotional side effects of T2D medications.

Conversely, Morris et al. (2005) in a longitudinal study found that people who made the transition to insulin injections were initially shocked and reticent, but later grew to accept insulin injections – many finding it empowering to be able to control their treatment. The study concludes that

healthcare professionals, by not addressing patients' initial fears about insulin, create barriers of resistance to adopting insulin. This suggests that with support, older people living with T2D can overcome their fears and integrate T2D management into their day-to-day lives in a positive way.

The adoption of exercise and dietary control has also been found to be restrictive for people living with T2D (Fagerli, 2007; Casey et al., 2010; Wycherly et al., 2012) and on the diets of the household (Wellard et al., 2008). Casey et al. (2010) found that older people living with T2D preferred structured support with exercising, in this case an educational programme, but tended to drift away from regular exercise when required to maintain the exercise regime under their own volition. They found that those living with co-morbidities were most likely to be 'derailed' from maintaining regular exercise following structured education. Wycherly et al. (2012) found that maintenance of dietary recommendations and regular exercise was not wholly an issue of motivation (as per Minet et al., 2011), but rather educational programmes offered free access to exercise and support on dietary change. Hence, older people living with T2D who engage with structured education and exercise, experience financial and access barriers to the continuation of exercise and dietary practices when structured programmes end. However, Malpass et al. (2009) found that exercise was found to frequently act as a 'gateway-behaviour' to wider self-management behaviour. It would thus seem that older people do experience both barriers and enablers to day-to-management but may be able to overcome them with consistent and accessible support.

### **Social, familial, interpersonal and healthcare professional roles in T2D self- management**

A tranche of studies expand the notion of 'people living with diabetes' beyond purposive, self-directed action to demonstrate how management of T2D is influenced by social networks and health service-related factors (Gomersall et al., 2011). Rajaram (1997) explored how families struggle to normalise diabetes within their lives, and maintain social acceptability – a process of adaption. Similarly, the work of Hunt et al. (1998) explored the relationship between personal understandings and self-care activity for people with diabetes and found that people were either self-active, other-active (others took care of treatment) or non-active. The study concluded that those who saw their illness as hereditary, or as the result of 'events' were least likely to be self-active. Other studies have shown that spousal support is a key element of successful T2D

management (Trief et al, 2003; Beverly et al, 2007). Trief et al (2003) found that spousal support was a greater predictor of engagement with dietary control and exercise. However, Beverly et al (2007, 2008) found both congruence and differences in the perspectives of older people living as couples who managed the condition. Equally, it is easy to see that family and spousal support is an enabler of successful self-management – but it is important to note that older people often live alone, are bereaved and live away from immediate family.

Parry et al. (2005) explored ‘cause and control’ beliefs related to T2D, and found that these shape the way that people living with T2D divide tasks and responsibilities between themselves and others. They suggest that people living with T2D are required to grasp that both the cause and treatment outcomes of T2D are partly, but not wholly, within their control; and that the resulting understanding sometimes leads to inappropriate delegation of care and treatment responsibilities by the person living with T2D. Oftedal et al (2010) looked at patients’ experiences of support by healthcare professionals and concluded that motivating healthcare professionals can enable patients to self-manage. People living with T2D reported that support should be underpinned by: 1) an empathetic approach; 2) practical advice and information; 3) involvement in decision-making; 4) accurate and individualized information; and 5) ongoing group-based support. Lawton et al. (2008) have found that personal understanding of T2D is informed by health service delivery. The study (ibid.) showed that patients’ health beliefs were intertwined with the health care services they receive, for example, patients may feel that their illness is not as serious as it is managed by their General Practitioner (GP) rather than a Diabetologist. The study also found where T2D was asymptomatic, medical tests (and self-monitoring devices) often actualised the illness for patients through showing physical effects and potential consequences. Indeed, there are numerous studies showing improvements in patient self-management relating to which healthcare professional leads their care. Studies have shown that regular and sustained access to multi-disciplinary teams (Cuddihy et al., 2011;) Practice Nurses (Bartol,2012; Edwall et al., 2008; Kruger, 2008); Diabetes Specialist Nurses (Edwall et al, 2010; Moser et al., 2008); Community Health Workers (Otero-Sabogai et al., 2010) and tele-health interventions (Wu et al., 2010; Jennings et al., 2009) are all associated with positive changes in self-management activity and outcomes. Other studies have also explored how experiences of T2D management can be also influenced by use of complementary medicine (Chang et al., 2012, 2011; Wang et al., 2011); improved through self-

help and peer-support mechanisms (Lindenmeyer et al., 2010; Baksi, 2010; Rygg et al., 2010; Simmons et al., 2010).

Day-to-day management of T2D is also shaped by experiences of clinical approaches, health services and organisational/systemic issues informing: 1) Perceptions of T2D and its management, 2) How responsibilities for care and treatment are divided up, and 3) That these social relations inform self-management styles (Nam et al., 2011). This suggests that the management of T2D at the patient/provider interface involves delegating, or assigning roles and responsibilities which create different styles, methods and strategies of self-management (Nam et al., 2011). Gomersall et al., (2011:14) note that in the T2D literature, self-management as a construct is frequently viewed as a means “...to regulate the self...”, as “...[t]here is a also moral dimension in that, after education and empowerment, should diabetes continue to be poorly managed, it is the individual patient who is construed as having failed”.. The assumption of self-management as relating solely to an individual’s capacity for purposive action or as a matter of educating patients to overcome the personal barriers they experience, can be seen as reductionist. As has been shown, how empowered the person is to self-manage is also shaped by factors outside the individual, including facets of health care systems inform peoples’ perspectives, understanding and experiences of managing T2D in a day-to-day context (Newton and Asimakopoulou, 2008; Gomersall et al., 2011).

Studies in the doctor-patient relationship, particularly those focused on patient-centring, argue that better health and well-being can – or ought to - be attained in professional-patient encounters where information – both personal and technical - as well as treatment and option-deliberation are shared between participants (Morgan, 2003; Coulter; 2002). Hiscock et al. et al. (2001:25) note five main expectations patients had of their encounters:

- Friendly, warm and ‘equal’ approach to the patient;
- Willingness to understand the impact of diabetes
- ‘Partnership approach’ to treating the condition
- Willingness to make time to answer questions
- Proactive approach to making referrals to other healthcare professionals

Studies have also highlighted the role of communication between healthcare providers and those living with diabetes. Communication barriers have been found to be exacerbated with cultural and ethnic difference (Kokanovic and Manderson, 2007; Jones et al., 2008; Chlebowy et al, 2010; and Peek et al, 2010), and by gender (Matthews et al., 2009; Morris et al., 2005). In terms of empowerment a more central concern has developed around the doctor-patient relationship – that of the assumption of an equipoise relationship, i.e. the notion that all options available are made available to both parties in the ‘empowering’ medical encounter (Newton and Asimakopoulou, 2008). Paterson (2001) interviewed patients considered to be expert in managing diabetes. The authors defined ‘expert’ as: “...having the ability to make trustworthy decisions about self-management and maintain good overall glycaemic control...” (Paterson, 1999: 576). A key finding was that people living with diabetes reported that equipoise relationships could be undermined in two key ways: 1) Experiential knowledge was felt to be routinely discounted by professionals; 2) Professionals often failed to provide the resources necessary for people to make informed decisions. This situation could also be further exacerbated by ageism.

### **The role of health system factors in T2D self-management**

Alazri et al. (2007) looked at the role of wider health system factors (such as service organisation and delivery) have on patient management of T2D. The study used focus groups to explore how people living with T2D valued continuity of care in their relationships with healthcare professionals. Patients reported valuing three types of continuity:

- Relational continuity – care from the same health professional;
- Cross-boundary (team) continuity – effective transition and good communication between services;
- Informational continuity – where information about the patient followed the patient during cross-boundary transfers.

Patients rarely reported experiencing these types of continuity. Alazria et al’s (2007) study suggests a greater role for systemic factors, such as service organisation, in shaping patients’ experiences and expectations of services, and informing their capacity to self-management. Wellard et al. (2008) showed that systemic factors such as long waiting times and lack of appointments influenced patients’ self-management decisions.

### **T2D-related factors and their influence on self-management**

One largely overlooked area of research into patient experiences of T2D is how illness itself creates physical changes in the body which impact on experiences of people living with T2D. One important aspect of Murphy and Kinmouth's (1995) seminal study is the notion of 'embodiment' where it is argued that a key catalyst to self-care behaviour is the ability of respondents to observe and respond to their own bodies. The authors noted that people living with T2D judge the utility of medical advice, by interpreting the efficacy of the advice through impact on the physical manifestations of T2D. This suggests physical changes in the body can impact on perceptions and experiences by people living with T2D. People living with T2D also manage multiple conditions and illnesses (Nam et al., 2011). Numerous studies of patient experiences (Bayliss et al., 2003; Jerant et al., 2005 and Visram et al., 2008) have found that co-morbidities are a major barrier to self-care activities in T2D. People living with T2D can be managing multiple conditions which pre-existed their diabetes diagnosis. They can also be managing conditions resulting from living with T2D, these can be: micro-vascular – e.g. diabetic neuropathy or retinopathy; or micro-vascular – e.g. cardiovascular disease, cerebro-vascular disease and coronary artery disease. Equally, co-morbidities can be any non-diabetes related acute illnesses or morbidities diagnosed following T2D diagnosis. Depression, for example is also linked to all of these aforementioned categories, and has been shown to alter perception of T2D self-management and is associated with increased morbidity, mortality and functional limitation – these physical outcomes (co-morbidities) are seen to have a bi-directional relationship with depression (Nam, 2011; Chao et al, 2005; Jennings et al., 2009).

However, managing co-morbidity is, for example, seen to impact positively on symptom interpretation. Beverly et al. (2011b) found that older women living with T2D who developed myocardial infarction spotted the symptoms earlier as not their 'typical' T2D symptoms. Similarly, Kreyenbuhl et al. (2011) found that people managing mental illness were better able to control blood glucose than those without mental illness, this skill was advantage conferred from managing multiple conditions. However, Kerr et al. (2007) found that patients with greater numbers of co-morbidities, like older people, placed lower priority on managing T2D and had low diabetes self-

management ability. Kerr et al. (2007) also found that only macro-vascular and non-diabetes-related co-morbidities were associated with de-prioritising self-management of T2D. Whereas living with higher numbers of micro-vascular, macro-vascular, and non-diabetes-related conditions were associated with poor self-management. Severity of macro-vascular conditions was negatively correlated with prioritising T2D self-management, i.e. the more severe the condition, the less the person self-managed. This suggests that managing T2D itself may not be the priority in patients' perceptions where a range of co-morbidities exist - such as older people. Although the realm of physical manifestations may impact in numerous ways on the perceptions of people living with T2D, it must be taken in the context of other illnesses. Although physical manifestations are an important influence on perception they are also interpreted through people's subjective experiences, as well as systemic and socio-contextual conditions (Song and Lipman, 2008).

### **Socio-contextual factors and their influence on self-management**

Far removed from exploring perceptions and understanding of the physical manifestations of T2D, studies have sought to identify socio-contextual factors that shape self-care practices and 'adherence' to T2D therapies (Brown et al., 2004). Maclean's study (discussed above), for example, found people's responses were influenced by individual factors such as character traits and gender; diabetes factors such as duration and severity of the condition; and contextual factors such as degree of family support available. Newton et al. (2015) looked at self-management styles by degree of purposive action by the individual invested, the type of support they drew on, stage of the condition and co-morbidities as well as relationships with healthcare professionals. Newton et al. (2015) found 6 self-management styles relating to the experiences of older people living with T2D. Older people self-managed T2D: (i) through routinisation; (ii) as a burden; (iii) as maintenance; (iv) through delegation; (v) through co-management; and (vi) through autonomy. The self-management styles identified also shaped the criteria people used to judge the success of their self-management practices. The findings showed that styles of T2D self-management were mediated and moderated by socio-contextual issues, and that there was some association between income group and style of self-management. This suggests that socio-contextual resources (e.g. familial and health service support and income) may precede, enable and hinder how people self-manage, and hold greater influence over peoples' ability to self-management than their day-to-

day, individual purposive efforts to overcome the immediate barriers and restrictions they experience.

Other studies have looked at ethnic and cultural differences (e.g. Kokanovic and Manderson, 2007 and Peek et al, 2010) highlighting how culture influences a person's perception of their illness. These range from exploring how ethnic and cultural difference shape: the patient- professional relationship (Peek et al, 2010; Jowsey et al, 2011); compliance with recommended clinical behaviours (Lawton et al., 2006b); and the unique lay understandings of T2D in different cultures (Lippa and Klein, 2008; Skelly et al; 2008). Elstad et al. (2008) used focus groups to explore experiences of living T2D in American Samoan communities. The study found that four factors perceived to cause T2D-related stress could be divided into:

- Individual stressors – physical symptoms;
- Familial stressors – Lack of support at home;
- Environmental stressors – Changes in food sources and dietary practices as access to food has changed from a subsistence way of life to one of living and working in a cash economy;
- Cultural stressors – cultural stress was associated with adapting to a rapid cultural and economic change in their community

Studies exploring experiences of T2D self-management and wider structural and social-contextual factors frequently see culture as a confounding variable in health outcomes which are to a greater extent influenced by socio-economic factors. This is because cultural and ethnic minorities tend to be over-represented in poorer socio-economic groups which is a causal factor in poorer health (Brown et al., 2004; Fagerli et al., 2007).

## **CONCLUSION**

In conclusion, we can see that the growth in the prevalence of T2D, which is a growing and particular issue for the older population, has led to concerns about how individuals adhere and comply with clinically-recommended behaviours. One key response has been the empowerment approach which seeks to empower patients to self-manage their condition. The empowerment approach fits well with a body of work focussing on the strategies people adopt to purposively manage their condition. However, it has also been shown that people living with T2D have



common barriers and enablers they experience in their efforts to self-manage. These barriers and enablers relate to levels and types of social support, the quality of healthcare support as well as access to, and quality of, health services and continuity of care. However, it is evident that experiences of self-management are further shaped by the stage of the condition and the presence of any co-morbidities. As with all illness and disease, outcomes as well as experiences are shaped by socio-contextual factors which precede and inform peoples' ability to self-manage the condition, and the resources they can devote to self-management. Given the evidence discussed above it is clear that a 'whole-system approach' is required that supports older people by enhancing their socio-contextual resources, which builds on their existing social support and takes into consideration the effects of T2D and its comorbidities on their ability to self-manage. This, in itself is perhaps a more universal way to ensure that living with T2D in older age becomes a positive ageing experience. Better understanding of older people's experiences of self-management at all levels – not just focusing on the individual's ability to meet clinically recommended behaviours - will enable more effective support of older people in managing their condition, avoid or reduce the likelihood of complications and maximise their chances of ageing positively.

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